PHENOMENOLOGICAL STUDY AN EXPLORATORY ON PARENTS OF AUTISTIC CHILDREN IN KUCHING, SARAWAK

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ABSTRACT

Autism spectrum disorder is an enigma as even with all the expertise of today's minds and revelations, it is still not well understood. This paper presents the findings of a study which explored the lived experiences of 12 parents of autistic children in Kuching using phenomenological methodology. These parents were randomly sampled from those who met the inclusion criteria. Information was collected through in-depth focused interviews which continued until data saturation. The sessions were audio-taped and transcribed. The data generated were analysed using Colaizzi's (1978) method of data analysis. The five major themes which emerged are: 1) Multiple negative feelings and behavior; 2) Stress in continuum; 3) Anger-love paradox; 4) Self blaming; and 5) Fear and phobia. Fathers were found to have relatively different view points toward their autistic children from the mothers. Other findings are impacts on siblings and relatives. These findings are particularly important in the light of recent government awareness of autism as a child disorder in community health. It draws attention to the needs of parents of autistic children to clearly and forcefully articulate and make visible their perspectives of living with their autistic children for advocacy of education, health care and other support services.

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CHAPTER I

INTRODUCTION

1.0 Introduction

This is a study regarding autism in Kuching, Sarawak using qualitative method. It aims at eliciting the lived experiences of 12 parents (11 mothers and one father) who have children with autism. It seeks to learn from these parents whose stories demonstrate the experiences and effects of living with these children.

Autism has great impact on human being, be it the sufferers, parents or professionals alike. Ellis (1995) describes it as a little understood disability globally. However, it is also a much misunderstood syndrome especially within the Malaysian context. Autism is a life-long disability that impairs a person's ability to understand information and communicate with others. It is more prevalent than ever before estimated, affecting roughly 1 in 150 American children (USAAA Weekly News, 2007). It is a spectrum disorder, which means that the symptoms and characteristics of autism can present themselves in a wide variety of combinations from mild to severe. Ellis (1995) asserts that autism is "a jigsaw with a missing piece". Mesibov, Adams and Klinge (1997) regard autism as a complex developmental disability due to a neurological disorder that interferes with the functioning of the brain. Baron-Cohen, Tager-Flusberg and Cohen (1993) purport that autistic individuals have

impairments in the development of the theory of mind. The child finds the world and especially other human beings totally bewildering, and has no idea of the effect of his or her behaviour on other people (Howlin, 1999). Baron-Cohen *et al.* (1993) describe that autism is characterized by a failure to develop the ability to make sense of the world, delay and deviance, particularly in the areas of communication, social interaction, cognitive functioning, sensory processing and behaviour. Autistic children have severe communication problems, difficulty relating to people, resistance to changes in routines or surroundings and a tendency towards repetitive behaviours (Salaza, Wright & Thomas 2001).

Generally, the early onset of autism can be diagnosed in a child by the age of 18 months. Some children develop normally, however after the age of three or four, autistic symptoms begin to emerge (Ellis, 1995). Some individuals with autism may also have other disorders such as epilepsy, intellectual disability, Down's syndrome, or genetic disorders such as Fragile X Syndrome. Approximately 25% to 30% may develop a seizure pattern at some period of their lives (Mesibov *et al.* 1997).

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1995) reports that boys are four times more likely to be affected by autism and the condition is more likely to affect the first born. There are no apparent differences in prevalence across racial, ethnical or socio-economic boundaries (Mesibov *et al*, 1997). Making diagnosis is difficult for professionals with limited exposure to autism, because the characteristics vary a lot. In order to have an accurate and effective identification of autistic children, evaluation should be

done by a multidisciplinary team of a neurologist, a psychologist, a developmental paediatrician, and a speech/language therapist (Simpson & Zionts, 1992).

The exact cause of autism has not been determined. Hyman, Rodier and Davidson (2001) argue that it occurs as a result of biological conditions including biochemical imbalances, neurological damages or genetic accidents. Vaccination has been suspected of being one of the causative agents. However, there is no concrete proof.

The diagnosis of autism commonly produces an overwhelming degree of devastation and confusion to parents. This is due to widespread feeling of hopelessness and ignorance about the condition. In order to understand the parents, being the closest care providers, this study aims to explore their experiences in coping with day-to-day existence with their autistic children. A phenomenological approach is selected to explore the phenomenon since it facilitates understanding of the complexity of being human in terms of feelings, thinking and behavior (Zabidah, 2001). Phenomenology is the study of "essences" of experience in an attempt to understand experience (van Manen, 1990b). A phenomenological approach that is as informal and sophisticated as it can be at a particular point of time, is selected to provide a constructed reality of experiences of parents of autistic children. Experiences of parents of autistic children are subjective phenomenon that are not well-articulated and are difficult to measure. Phenomenology seeks to uncover meaning from the experiences and allows the researcher to answer the broad question of "what it means to parent an autistic child'.

1.1 Background of the study

A family with an autistic child experiences much frustration and may even think that the child is simply out to make life difficult for them (Lawson, 1994). Burr (1998) expresses that parents face special challenges as they deal with their children's emotional isolation, repetitive behaviors, and impairments in social development, intelligence, and language. A local study by Zasmani (1993) reviewed that autism in children has significant impact on different aspects of the family system and the behavioral characteristics of the child present significant stress on parents. This is because, to most parents, a child reflects a personal achievement as many parents harbor high hopes and aspirations for their children. Zasmani (1993) further describes that a normal child may be seen as a reflection of personal adequacy, while a handicapped child indicates a sense of failure. Parents of a handicapped child undergo an intense crisis after they first learned of the diagnosis. They express negative feelings of grief, hopelessness, anger or rejection and even depression. Their grief is over the loss of a "perfect child" they have expected and they undergo a long process of acceptance of the handicapped child. This grieving process is probably a life-long one and is somewhat different from the usual grief process after the death of a loved one. This is because as the autistic child passes through each developmental stage in his life, the parent will be reminded of the child's disability and the grief may start again, although the intensity will be less.

Parents of autistic children generally experienced embarrassment, disappointment and more difficulties when taking the children out to public places (Zasmani 1993).

Howlin (1999) supports the statement by further describing that the children are more physically dependent on their parents for care and are more disruptive on family activities. To the on-lookers, the autistic child is seen as misbehaving and poorly-disciplined rather than as a child who is mentally challenged.

Not only do most autistic children have normal physical features, a majority of them can be considered to be exceptionally attractive (Simpson & Zionts, 1992). Hence, by anecdotal evidence, parents of autistic children in Kuching do not receive the same sympathy and attention as those who are having children with physical disability.

It has been stated by Zasmani (1993) that the characteristics of the autistic children are significant predictors of parental stress. She further expresses that the sources of stress which are common to these parents include the ambiguity of autism, the severity of its social and cognitive deficits, the life-long duration of autism and the lack of its congruence with social norms. The language impairment in autism interferes with the feeling of closeness towards the child. Parents find their autistic children complex, difficult to understand and establish attachment. Many wish that they will one day find the "key to unlock" this communication gap between them and the children.

Although there is no published research in Sarawak pertaining to autism, the researcher is aware that a British Executive Service Oversea (BESO) volunteer, Patricia Smiths had presented a report on 'Autism in Sarawak' in World Forum

Centre for continuing professional development – Multi-Disciplinary Conference held in York University on 15th April, 2003. Patricia had been attached to the Kuching Autistic Resources and Educational Centre, Kuching for a period of six weeks. Anecdotal evidence showed that parents of autistic children in Kuching feel vulnerable because support is very thinly stretched. Research studies in this area are needed to understand the perspective of these parents living with autistic children in Sarawak. Such information is needed for the public to understand better the odd behaviour of autistic children, know the specific techniques required in handling them and helping in accepting autistic children in society. This study in Sarawak to uncover parents' experiences of having autistic children is very much needed at this point of time.

From a qualitative perspective, language and the ability to express oneself to others is the only way one can bring experience into a form that is understood by others (van Manen, 1990a). The qualitative paradigm appears to be the appropriate choice because of the apparent dearth of basic information and research, particularly within the ambit of social work pertaining to autism. Lee (1999) describes that by using phenomenological perspective approach, the ultimate aim is to facilitate the process of becoming more fully human. The finding from this research based on parents' voices about what it is like to be coping with difficult autistic children in their lives will enable the authorities concerned to carry out the necessary intervention both for the autistic children as well as their parents in Kuching. Underpinning the study is the question "what is it really like to have and live with autistic children?"

1.2 Statement of the Problem

Autism is a condition which is little understood, especially within the Malaysian context and often not recognized or diagnosed outside specialist circles (Ellis, 1995). The awareness, knowledge and understanding of autism among the public in Kuching is scanty and the condition is largely misunderstood and even unknown. Isolated in a world of their own, people with autism in Kuching need help to fit in. There is little public awareness about the disorder that, in some form, may strike more than 1 in 400 children (Autism Today, 2007). Although this describes the situation elsewhere, it is also true in Malaysia generally and Sarawak specifically. It is time to recognize that these children are suffering from a potentially manageable medical disorder and need our clinical and social work research efforts now. A study by Simpson and Zionts (1992) posit that the complexity of the disorders leave people in the United States with many unanswered questions. Likewise in the Sarawakian context, there are still many people who are unaware of the existence of such disorder. Therefore, there is obviously an overwhelming need for autism awareness and education in Kuching.

There are very few specialized resources for children and people with autism in Malaysia and these are mainly formed by desperate parents and some professionals in Malaysia as non-governmental organizations (NGOs). In Peninsular Malaysia, there are more than ten centers providing special remedial education for autistic children. One of them is the National Autistic Society of Malaysia (NASOM) in Kuala Lumpur which schools about 200 autistic children (NASOM Bulletin, 2007).

In Sarawak, the Kuching Autistic Resource and Educational Centre (KAREC) provides educational services for about 40 autistic children (Personal communication, 22 December 2007).

In Kuching, these children's needs are not being attended to and many of them are being sent to the school for Mentally Handicapped or to special education classes in government schools. They are being taught together with children who have different learning disabilities, notably Down syndrome, dyslexia, cerebral palsy, hyperactivity disorder and slow learners. More often than not, these autistic children are left alone in the corner to indulge in self-stimulatory behavior. In these situations, the autistic children do not improve much as they need a special and highly structured educational program tailored to their disorder (Lovaas, 1987). It is suspected that many of the parents just leave their children there hoping the teachers or therapists will perform miracles of improvement or cure on their children.

There are few parents who believe that the present educational system in Sarawak does not improve their autistic children. Placement of this group of unfortunate children in School for the Mentally Handicapped (PERKATA) is the least that they want. Together with the help of some professionals and businessmen, Kuching Autistic Resource and Educational Centre (KAREC) was set up in 1999 as a response to the growing concern that the needs of this diverse population go beyond existing provision.

A survey done by Kuching Autistic Association in 2001 showed that the number of registered children with autistic characteristics in Kuching, Sarawak is only 219. This survey may reflect a lower prevalence of autism than in reality because of parental ignorance and failure to detect people who have not sought services for autism and who have been misdiagnosed.

Marchand (2002) asserts that autism research is still in its infancy stage and the causes of it appear to be multi-factorial in its biology. In general, relatively little has been written on autism in our country as compared with what has been published on autism in the United States of America and elsewhere. Following scrutiny of available articles, only two research studies which explored autism-related topics have been done in Malaysia (Zasmani, 1993).

In Zasmani's (1993) study which was done in Kuala Lumpur, she posits there is an overall greater parenting stress in mothers of autistic children than those mothers with other developmentally and physically disabled children. Obviously, parents of autistic children do not receive the same attention and sympathy as those having wheelchair-bound children. Research in autism fills a much needed gap in identifying the strengths and pitfalls of different approaches and is a welcome asset in a field where too little is known in our country. Besides the report presented by the BESO volunteer, there is no published work related to autistic children in Kuching. Consequently, my study is designed to bring to the forefront to explore the lived experiences of parenting autistic children in Kuching based on a phenomenological approach.

1.3 Research Aims and Objectives

To understand the parents' lived experiences with their autistic children with regards to the following aspects:

i) psycho-emotional impact on parents

ii) social impact on family activities

iii) financial constraints

iv) education of their special children

v) coping strategies

1.4 Significance of the Study

This study which aims at exploring how parents of autistic children in Kuching are struggling with the care of their autistic children will enable the community to be more understanding on the perspectives and feelings of parents of autistic children. It is hoped that the community will realize that the families need to be supported by a society that is committed to helping them with the bringing up of their special children.

The increase in knowledge of autism and the impact of autistic children on the families will help professionals in the management of these children as well as their families because of the reciprocal relationship in the family system, that is, one influencing the other. The knowledge of how an autistic child affects the parents, especially the mother, being the usual closest caregiver, will help professionals

develop coping strategies among mothers with autistic children to reduce their stress before it occurs or results in maladaptive behavior. Therefore it is an attempt to reduce psychiatric morbidity among parents.

The phenomenological approach used in this study explores the needs and experiences of parents encountered in the care of autistic children, at a depth often not previously sought. It brings feelings and experiences to life, enabling others to catch a glimpse of the otherwise unknown. It calls for the participants to narrate an experience and for the researcher to interpret that interpretation (Polit & Hungler, 1999). The knowledge and understanding gained by adopting a phenomenology perspective can help the researcher to fulfill the definition of a mother, to be 'with women' (Donnison, 1988 cited in Cluett & Bluff, 2000) and facilitate improvements in practice.

The findings of the study have the potential to enable health professionals and nurses specifically, to become more sympathetic and understand more deeply the lived experiences of both the autistic children and their parents. Nurses are frontline health care providers, hence they need to respond holistically to the health needs of both the autistic children and their parents. It is essential that both the nursing profession and society understand the existential impact of autistic children.

It is hoped that this study will help the autistic children to be understood and more accepted by the society and the public will be able to respect them for who they are – a fellow human being, but with special needs. In addition, this research project will

be able to form the basis of our lobby for awareness, improved service and increased expertise in the area of autism. It is hoped that the outcome will be justifiable for the Ministry of Education to develop appropriate centers or schools nation-wide to educate autistic children to be independent and productive citizens.

1.5 Operational Definitions / Clarification of Terms used in this study

For the purpose of this study, the following operational definitions are used:

1.5.1 Psycho-emotional impact

It refers to the myriad psychological and emotional impact of having an autistic child in the family (Longman Dictionary of Contemporary English, 2003).

1.5.2 Social impact

Social impact is the effects of an autistic child have on the family's social activities and relationships (Longman Dictionary of Contemporary English, 2003).

1.5.3 Phenomenological Approach

Phenomenological approach is a process of exploring, examining, analyzing, learning and constructing the meaning of human experiences through intensive dialogues with persons who are living the experience (van Menan, 2002). Crotty (1996) describes it as a philosophy and method which allows researcher to better understand the world of his/her participants.

1.5.4 Lived Experience

Lived experience is the 'originary' way in which we perceive reality (Morse, 1991). It refers to the parents' reflection of meaning of day-to-day experiences of living with their autistic children.

1.5.5 In-depth Interviews

It refers to repeated face-to-face conversations between the researcher and parents of autistic children directed toward understanding parents' perspectives on their lives, experiences or situations as expressed in their own words (van Menan, 2002).

1.5.6 Parents' Perspectives

Parents' perspectives refer to parents' opinions, feelings and knowledge of their autistic children (Longman Dictionary of Contemporary English, 2003).

1.5.7 Special Needs Children

It refers to children with development disabilities (or with mental challenges) including autistic children (The Advanced Learner's Dictionary of Contemporary English'2003).

1.5.8 Qualitative Methodology

This research method explores all dimensions of human uniqueness (Beanland, Schneider & LoBiondo-Wood, 1999). In-depth interviews and participant

observations are used to collect data. The main purpose of this method is to understand the parents' experiences of living with their autistic children.

1.5.9 Data Saturation

Data saturation occurs when the information shared with the researcher becomes repetitive (Lincoln & Guba, 1985). It occurs when there are no more new ideas from all the participants.

1.6 Chapter Summary

This chapter commenced with describing the current scenario of autism. The background of the problem relates the many problems faced by parents of autistic children in Kuching. The statement of problem was given to support the reasons for conducting the study. Objectives of the study were spelt out to lead to the formulation of research questions. The significance of the study was also discussed. To help readers to have a better understanding of the study, operational definitions in the study were also given. In the next chapter the researcher will discuss and present the literature review pertaining to the study.

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